

GOOD PRACTICE GUIDE

**‘Significantly
impaired decision-
making ability’ in
individuals with
eating disorders**

REVIEWED JUNE 2017

This document was reviewed in Spring 2017 in light of changes to the Mental Health Act. We found no changes were required. It was originally published in April 2014.

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Our aim

We aim to ensure that care, treatment and support are lawful and respect the rights and promote the welfare of individuals with mental illness, learning disability and related conditions. We do this by empowering individuals and their carers and influencing and challenging service providers and policy makers.

Why we do this

Individuals may be vulnerable because they are less able at times to safeguard their own interests. They can have restrictions placed on them in order to receive care and treatment. When this happens, we make sure it is legal and ethical.

Who we are

We are an independent organisation set up by Parliament with a range of duties under mental health and incapacity law. We draw on our experience as health and social care staff, service users and carers.

Our values

We believe individuals with mental illness, learning disability and related conditions should be treated with the same respect for their equality and human rights as all other citizens. They have the right to:

- be treated with dignity and respect
- ethical and lawful treatment and to live free from abuse, neglect or discrimination
- care and treatment that best suit their needs
- recovery from mental illness
- lead as fulfilling a life as possible

What we do

Much of our work is at the complex interface between the individual's rights, the law and ethics and the care the person is receiving. We work across the continuum of health and social care.

- We find out whether individual care and treatment is in line with the law and good practice
- We challenge service providers to deliver best practice in mental health and learning disability care
- We follow up on individual cases where we have concerns and may investigate further
- We provide information, advice and guidance to individuals, carers and service providers
- We have a strong and influential voice in service policy and development
- We promote best practice in applying mental health and incapacity law to individuals' care and treatment

Why we wrote this guidance

Significantly impaired decision-making ability (SIDMA) is one of the grounds for compulsory treatment under the Mental Health (Care and Treatment) (Scotland) Act 2003 (the 2003 Act). It must be considered before an individual is subject to civil compulsory treatment, although it does not apply for individuals who are treated under the 2003 Act having been accused of, or committed, an offence.

The 2003 Act does not define SIDMA. The code of practice makes some attempt to state what SIDMA means. But it is up to the medical practitioner to assess whether or not the individual has SIDMA. The Mental Health Tribunal will test this assessment for all applications, reviews and appeals.

We heard concerns that the SIDMA criterion was hard to interpret for individuals with eating disorders. It is a relatively new concept in mental health law in Scotland. In other jurisdictions, notably England and Wales, there is no requirement to consider the individual's capacity to make his/her own treatment decisions, although mental health practitioners will take this into account when deciding on the need for compulsory treatment.

We wanted to look at how the SIDMA test can be applied to individuals with eating disorders where treatment under the 2003 Act is being considered.

The use of mental health legislation for individuals with eating disorders

It is beyond the scope of this guidance to determine the benefits and drawbacks of the use of compulsory treatment for individuals with eating disorders. Broadly, the relevant literature tends to suggest that it depends on how it is viewed by the individual.

Some research suggested that interfering with individual autonomy leads to a worse outcome but this is not a consistent finding¹. An important finding is the importance of relationships. If compulsion is used within a framework of good relationships among the individual with an eating disorder, parents and professionals, it can be viewed positively. And it is important to remember that informal coercion occurs².

We think compulsory measures have a place in the treatment of individuals with eating disorders. In anorexia nervosa, there can be serious risks to the individual if weight loss is extreme. The risk of coercion without the use of formal measures is that the individual does not have the protections available under the 2003 Act.

1 Ayton, A., Keen, C. & Lask, B. (2009) Pros and cons of using the Mental Health Act for severe eating disorders in adolescents. *European Eating Disorders Review*, **17**, 14–23

2 Tan, J. O. A., Hope, T. & Stewart, A (2003b) Anorexia nervosa and personal identity: the accounts of patients and their parents. *International Journal of Law and Psychiatry*, **26**, 696–707

Protections include:

- The requirement to demonstrate that care and treatment comply with the statutory principles of the 2003 Act;
- The individual's ability to apply to the Tribunal for the order to be revoked or varied;
- A Tribunal hearing before treatment can continue under a compulsory treatment order;
- The provision of Legal Aid for legal representation at a Tribunal (although the patient or named person can choose a representative who is not legally qualified, if they wish);
- Safeguards for medical treatment, notably artificial nutrition without consent and administration of medication beyond two months.

In this regard, it is important to consider human rights legislation. All actions must accord with the articles of the European Convention on Human Rights.

Relevant articles include:

- Article 2: the right to life, where failure to intervene may lead to danger of death;
- Article 3: the right to be free from torture and other inhuman or degrading treatment;
- Article 5: the right to liberty and security of the individual. Any infringement of Article 5 rights should allow the individual a right of appeal;
- Article 6: the right to a "fair trial". This includes the right to a fair procedure in relation to civil rights and liberties;
- Article 8: the right to respect for private and family life. Any interference with Article 8 rights must be necessary, proportionate, pursue a legitimate aim and be in accordance with the law.

Regardless of legal status, anyone with an eating disorder has the right of access to independent advocacy and can make an advance statement about treatment that she/he would or would not wish.

SIDMA – what does it mean?

Specifically, SIDMA applies to medical treatment. The 2003 Act requires the medical practitioner to determine:

- The presence of mental disorder (defined broadly but with some important exceptions³);
- The availability of medical treatment (defined broadly⁴);
- The presence of SIDMA in relation to that treatment;
- Risk (to the individual's health, safety or welfare or the safety of any other person);
- The necessity of an order.

In relation to individuals with eating disorders, all five grounds must be considered.

3 See section 328 of the Act <http://www.legislation.gov.uk/asp/2003/13/section/328>

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We are focussing on the SIDMA test. However, when considering SIDMA, the practitioner is also considering the availability and effectiveness of the medical treatment, risk and necessity.

While SIDMA is not defined, there are two relevant definitions relating to incapacity and medical treatment in Scotland.

1. The Adults with Incapacity (Scotland) Act 2000 defines incapacity as being incapable of acting, or making decisions, or understanding decisions, or communicating decisions or retaining the memory of decisions by reason of mental disorder or inability to communicate due to physical disorder.
2. Case law had determined that, in order to be able to consent to medical treatment, the individual must be able to:
 - (a) Understand the information relevant to the decision,
 - (b) Retain that information,
 - (c) Use or weigh that information as part of the process of making the decision,
 - (d) Communicate his decision (whether by talking, using sign language or any other means).

The latter definition formed the basis for the definition of incapacity in the Mental Capacity Act for England and Wales. It also appears in the code of practice for the 2003 Act. The two definitions are compatible when it comes to medical treatment, but the second definition is more specific to treatment decisions.

It is essential to remember that capacity is decision-specific. The individual may be capable of making some decisions about medical treatment but not others.

SIDMA in general

An analysis published in 2010 showed five broad categories of reasons given for SIDMA: "lack of insight, cognitive impairment, presence of psychosis, severe depressive symptoms and learning disability."⁵

These were statements made on forms supporting or authorising compulsory treatment. Some statements did not appear to provide sufficient justification of the SIDMA criterion. The analysis stated that it is necessary for the medical practitioner to justify clearly how the SIDMA criterion is met, rather than simply reiterating that SIDMA exists. The question of the significance of the impaired decision-making is one for the Tribunal to decide after hearing evidence.

SIDMA applies to the whole package of medical treatment. While an individual may have SIDMA in relation to the totality of medical treatment needed, he/she may have capacity to consent to individual treatments or to refuse certain treatments.

5 Shek, E., Lyons, D. & Taylor, M. (2010) Understanding 'significant impaired decision-making ability' with regard to treatment for mental disorder: an empirical analysis. *The Psychiatrist*, **34**, 239-242

SIDMA in individuals with eating disorders

The broad guidance outlined above is not specific enough for individuals with eating disorders. Given the complexities of thought processes and distorted body image, we thought more specific guidance was needed. We used the assistance of a wide group of stakeholders to provide more detailed guidance.

We invited practitioners, legal experts, individuals with eating disorders and carers to a consultation event. We asked them to reflect on their own experiences and we used anonymised case examples to provoke discussion. We also gave them examples of statements justifying the SIDMA criterion for compulsory treatment.

We asked them to consider what constitutes ability or inability to make decisions about treatment for an eating disorder. Based on this, we asked them to decide which were the best and worst descriptions of SIDMA from the statements we gave them.

1. Capacity to make decisions

Participants generally agreed on the features of individuals with an eating disorder that would make them capable of making their own decisions about treatment.

These were:

- An understanding of the risks associated with poor nutrition and weight loss. This is more than a general understanding; the individual must be able to understand the specific risk to her/his own health or welfare.
- Linked to this, the individual may have capacity to decide to take risks. Making unwise or emotionally-driven decisions may not necessarily mean the individual lacks capacity. We discuss this further below.
- The decision is not being affected by impaired brain function due to starvation or significantly depressed mood.
- Decisions should be free from coercion by others. Well-meaning carers and practitioners should do their best to persuade the individual that a particular approach will be of benefit. But there is a risk that this becomes coercion of an unwilling individual who lacks capacity and would be better protected by the safeguards of mental health legislation.
- Consistency of decision-making. The individual may make statements suggesting an understanding of the disorder and the risks, but it is important that behaviour is consistent with this apparent understanding.
- An ability to retain information.

2. Impaired decision-making ability

Some degree of impairment of decision-making ability is likely when an individual has an eating disorder.

The reasons for this are:

- "Anorexic cognitions." These refer to the distortion of thinking that occurs in anorexia nervosa, e.g. distorted body image, desire to lose weight even when significantly underweight and an irrational fear of gaining weight.
- Taking action to lose weight or avoid gaining weight by reduced food intake, excessive exercise, vomiting or using laxatives.
- Despite apparently recognising the condition and agreeing that treatment is needed, behaving in a way that continues or worsens it, e.g. by adopting tactics to avoid eating or being accurately weighed.
- Depressed mood. For example, the individual recognises the presence of anorexia nervosa but feels so unhappy that she/he would rather die than gain weight. In chronic cases, this may lead to a difficult ethical dilemma about continuing or withdrawing compulsory treatment.
- Impaired cognitive function. Prolonged starvation can affect speed of thought, ability to think clearly and rationally and may cause memory damage. This is highly likely to impair decision-making.

3. "Significantly" impaired decision-making ability

When does impairment become "significant"? Or, as some of the consultees put it, "when does IDMA become SIDMA?" Given that some impairment of decision-making ability is likely, the area of uncertainty is the point at which this becomes "significant" in terms of the 2003 Act. Given that the Act does not define SIDMA, practitioners and the Mental Health Tribunal need to consider this on a case-by-case basis. We wanted to produce some guidance as a framework for considering this.

The presence of anorexia nervosa does not necessarily mean that the individual has SIDMA. The Scottish Parliament intended that the test of decision-making ability was an essential component in determining whether or not the individual should be treated on a compulsory basis. Assuming that any one individual diagnosis automatically means that SIDMA is present would be contrary to Parliament's intention.

The SIDMA criterion is separate from the criteria of risk and necessity. But discussion often centred around whether or not the individual had an understanding of the risks of starvation. So while SIDMA and risk are separate criteria and must be justified separately, ability or otherwise to appreciate risk is an important consideration. We deal with the issue of necessity below.

Using the views of participants in the consultation process, we suggest that the following factors might suggest that impaired decision-making ability has become "significant" in terms of the 2003 Act. These factors may become more apparent when the individual's eating disorder worsens.

The first two relate to thinking and behaviour patterns:

- Extreme rigidity of thinking. This may occur even without mood disorder or cognitive impairment. The individual's thinking and behaviour is so focussed on food and weight that she/he lacks the ability to perceive or accept the risk of present or further weight loss. Reducing food intake and excessive exercise dominate the individual's life.
- Inconsistency in decision-making. The individual may appear at interview to understand the condition and the risks but behaves differently. In particular, individuals may give the appearance of having capacity and agreeing to treatment. But she/he is observed to disguise the extent of the disorder and act against the apparent decision to accept treatment. This emphasises the importance of taking account of the views of others when assessing SIDMA.

The next factors refer to conditions that arise from anorexia nervosa or often accompany it.

- Cognitive impairment. If tests demonstrate that starvation has caused brain function to become impaired, this is highly likely to constitute SIDMA. Examples include inability to remember information, concentrate enough to be able to absorb the information and have sufficient "executive function"⁶ to be able to weigh and balance information.
- Depressed mood. The presence of low mood is highly likely to lead to SIDMA. We have already considered the situation of the individual who would rather die than gain weight. But depressed mood may also lead to the individual failing to understand or process information.

4. Compliance versus consent

One of the risks of interpreting the SIDMA criterion is that the individual may be regarded as capable of consenting to treatment and incapable if refusing. We urge practitioners to use the definitions of (in) capacity referred to in this guidance. Compliance with treatment does not necessarily indicate capacity to consent.

Also, there is the issue of coercion to consent to treatment. The threat, explicit or implied, of compulsory treatment may result in the individual "complying", but only to avoid being treated under mental health legislation. Practitioners may also be reluctant to use compulsory measures because of the way this is perceived by the individual or carers.

This means that the necessity criterion needs careful consideration. Practitioners may consider that compulsory treatment, when the other four criteria are met, is not necessary because the individual complies. If this compliance is only to avoid compulsory treatment, the practitioner should give serious consideration to compulsory treatment, so that the individual has the protection of the safeguards of the 2003 Act.

For the individual who lacks capacity but does not resist or object to treatment, it may be appropriate to treat using part five of the Adults with Incapacity (Scotland) Act 2000 or, if the individual is under 16, by obtaining parental consent. Again we urge caution here as the 2003 Act gives greater safeguards if treatment is particularly restrictive of liberty or invades private or family life.

6 Kingston, K., Szmukler, G., Andrewes, D., Tress, B. & Desmond, P. (1996) Neuropsychological and structural brain changes in anorexia nervosa before and after refeeding. *Psychological Medicine*, **26**, 15-28

5. Decision-making ability and palliative care

One of the most difficult ethical areas is a decision to stop actively intervening in chronic cases. The individual's view, after long periods of treatment that have had no lasting benefit, may be that the burden and distress of further intervention are not justified.

These are rare and difficult situations that need detailed discussion on an individual basis. We encourage practitioners to take a wide range of views into account, including independent professional opinions. In terms of SIDMA, we advise taking account of the factors outlined in this guidance. Other factors need to be considered, for example, the availability of medical treatment that is likely to produce benefit.

Documenting SIDMA

We identified several statements from forms authorising, or applying for, compulsory powers under the 2003 Act. Part of the consultation process involved asking participants to assess the statements documenting SIDMA. We wanted to determine which were good and bad descriptions.

Example A

"X is not complying with her food plan and is therefore under-nourished. Her brain will not have sufficient energy to help her understand and retain information. She struggles to communicate her feelings consistently as a result of this. Her depressed mood also affects her decision-making ability as her cognitions are slow and she cannot see anything positive about her future. X thinks that she is eating enough in hospital and states that she will not eat at home. X believes that she is fat and refuses to eat full diet."

Most participants rated this as a relatively good description of SIDMA. Comments included:

- Highlights physical effects of starvation on cognition;
- Highlights mood disorder;
- Was specific to the individual;
- Good reference to capacity assessment although could have said more about weighing and balancing information in order to make decisions.

Example B

"Despite X being advised of the physical consequences of continuing not to eat, both short and potential long term complications, she refuses to eat food or have naso-gastric feeding. Despite being under-weight she does not want to eat as she believes this would make her fatter. In the week prior to admission, X was not compliant with Fluoxetine medication despite her low mood. She thinks it is normal for her not to eat. X does not believe other people including medical staff when they tell her that she is not fat and does not care about the effects of starvation. She does not want to remain in hospital. She has been advised that her liver function tests have become slightly abnormal which is likely to be due to her malnutrition but still will not eat."

Again, this was considered a good statement.

- Good description of anorexic thinking, again specific to the individual;
- Includes actions as communication as well as thoughts.

Example C

"X's anorexic thoughts are so strong that her insight is markedly impaired. She does not believe herself to be under-weight and despite being informed about the serious risks of anorexia has been unable to comply with her food plan consistently. She has said very clearly that she does not wish to gain weight."

This was rated as adequate but could be improved. While other parts of the form may have identified risk, the statement only refers to information about the risks of anorexia in general. It would have been better if it documented her views about information on the specific risk to her.

Example D

"By its nature, anorexia nervosa is a condition which makes it very difficult for patients to accept treatment (including adequate nutrition) even if fasting the patient is accepting of the need for treatment including adequate re-feeding. The patient struggles to eat enough, and aims to burn calories. It is due to the rigidly held beliefs that body image and emotions are associated with behaviours and this is how to bring about recovery that the patient's ability to make decisions about treatment are significantly impaired."

Participants considered this to be a poor statement. Comments included:

- Had nothing about the individual. It read like a paragraph from a textbook;
- Not person-centred, too concrete.

Example E

"X was finding it hard to understand and process information because of her poor physical health."

This was generally regarded as one of the worst statements. Comments included:

- Does not mention mental disorder at all, let alone anorexia.

Conclusion – how to justify and document SIDMA

From this consultation exercise, we were able to identify the factors that needed to be considered when considering the SIDMA criterion in the 2003 Act. There are grey areas where discussion on an individual case will determine whether or not SIDMA exists. We hope this guidance will help practitioners and Tribunal members when having these discussions. We also hope it will help individuals with eating disorders and their carers understand the basis for deciding on the SIDMA criterion.

From all the above discussion, we conclude that a good description of SIDMA will be understandable to non-medical persons (including the individual with an eating disorder) and contain:

- A specific description as to why this particular individual has SIDMA without making generalised statements about the condition;
- An explanation as to which features of the condition are interfering with decision-making. In the case of anorexia nervosa, this will include at least one of these three: cognitive impairment, mood disorder, severe anorexic thinking or behaviour (notably eating restraint, distorted body image perception, fear of weight gain, extreme desire to lose weight in spite of starvation and excessive exercise);
- A specific reference to which parts of the decision-making process (understanding, retaining, weighing and balancing information and coming to a decision) are impaired and why;
- A description, where relevant, of the extent to which the individual understands the condition and the need for treatment. We advise against blanket terms such as “lack of insight”;
- Again where relevant, a description of inconsistency in decision-making, especially where what the individual says and the way she/he behaves are different.

While we focussed this discussion on individuals with eating disorders, this guidance is likely to be helpful when considering and documenting SIDMA in other conditions.





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